CENTERS OF EXCELLENCE IN CANCER COMMUNICATIONS RESEARCH (CECCRs)

I. Overview

This initiative is the centerpiece of the National Cancer Institute's (NCI) Extraordinary Opportunity in Cancer Communications. The novelty and scope of this initiative reflects the NCI's recognition that effective communications can and should be used to narrow the enormous gap between discovery and applications and to reduce health disparities among our citizens. The RFA uses the P50 centers mechanism to invite applications for Centers of Excellence in Cancer Communications Research (CECCRs). The Centers will include three or more individual research projects which reflect hypothesis-driven research, pilot or developmental research projects, shared resources and career development. To be effective, the Centers' research should integrate cancer communications appropriately into one or more contexts of the cancer continuum--from prevention through treatment to survivorship and end-of-life research. Communications research is needed about challenging topics such as cancer information seeking, decision making under uncertainty, and genetic testing. Centers' research also should provide insight into mechanisms underlying how people process information. It is expected that the Centers' interdisciplinary efforts will result in new and/or improved syntheses, theories, methods and interventions, including those for diverse populations. The Centers will provide essential infrastructure to facilitate rapid advances in knowledge about cancer communications, translate theory and programs into practice, and train health communication scientists.

II. Background

Healthy People 2010 defines health communication as the research-based crafting and delivery of messages and strategies to promote the health of individuals and communities.

Communication is central to the effectiveness and quality of cancer care, from primary prevention to survivorship (Institute of Medicine (IOM), 1999) http://www.iom.edu Communication can raise awareness of health problems and recommended actions, give people the information they need to make informed cancer-related decisions and motivate action. The framers of the National Cancer Act of 1971 (and the subsequent amendments to that Act) were acutely aware of the central importance of cancer communication. Thus, they mandated that the National Cancer Institute (NCI) provide a program to disseminate scientific and other information regarding the causes, prevention, detection and treatment of cancer. Pursuant to this mandate, and mindful of the dramatic changes in the technologies of both health care and information, the NCI has dramatically expanded its commitment to cancer communications to ensure that all Americans have access to the cancer information they need and are able to use it effectively. As articulated in the Fiscal Year 2001 NCI Bypass Budget, the Institute is committed to improve knowledge about, tools for, access to, and use of high quality, evidence-based cancer communications regardless of race, ethnicity, health status, education, income, age, gender, culture, or geographic region.

Health communication research is a vibrant field concerned with the powerful roles performed by human and mediated communication (Kreps, Bonaguro, & Query, 1998). A wide range of scientists and communicators have been studying the process of effective communication and its impact on health for more than 25 years (Hornick, 1997). There are increasingly refined theories

of information processing, health communications and health behavior, including those that focus on how people represent and process health information, respond to cancer-related risks and change cancer-related behaviors. Intervention research on effective health communications has contributed to increasing proportions of Americans eating at least five fruits and vegetables per day, obtaining breast and cervical cancer screening, as well as to declining rates of smoking among many groups.

Changes in the role and accessibility of information are altering health care practices, patient-physician relationships and the way consumers and patients acquire and use information (Eng, et al., 1998; 1999; Patrick, 1999). Activated, empowered patients and direct-to-consumer advertising are changing the nature of doctor-patient communications, but more must be known about the impact of these altered relationships. Home computer and Internet use are on the rise, with a recent survey reporting that in the year 2000, personal computers were in 58 percent of all U.S. households, and 51 percent of all U.S. households had Internet access (PC Data Online, 2000). Approximately 70 million people searched for on-line health information in 1999, and cancer information was one of the most sought-after topics (Cyber Dialogue, 2000; Harris Poll, 1999). Both consumers and professionals have, or will have, a host of new opportunities for creating, distributing and acquiring health information from the World Wide Web, individually-tailored print and multimedia materials, interactive computer games, interactive kiosks, wireless devices, and many other channels and sources. NCI has supported some of the groundbreaking research in these areas. Much already has been learned. However, empirical evidence is critically needed about the efficacy and effectiveness of health communications interventions using these modalities. Data especially are needed about how these strategies can be used to meet the needs of diverse populations. With the rapid pace of discovery in the basic and clinical sciences, the aging of the U.S. population, the increasing population of cancer survivors, and the growing number of households in which someone is a caregiver for a person with cancer, the need and demand for high quality cancer information will grow.

There is a long tradition of research on doctor-patient communication and patients' comprehension of medical information (Roter & Hall, 1992; Whaley, 2000). However, important changes are occurring in the communication landscape. Patients are increasingly being asked to make decisions about health care choices, such as whether to get a prostate specific antigen (PSA) test or what treatment to choose for breast or prostate cancer (e.g., Entwistle et al., 1998), and these decisions must be informed by effective communication. A significant proportion of patients are not satisfied with the communication component of their health care interactions, and want more information than they receive (e.g., Thorne, 1999). The development of effective interventions and tools for informed decision making should build upon the wealth of available evidence from fields such as education, instructional design, cognitive science, social psychology, and human factors research. More research is needed on a variety of topics related to doctor-patient communication and informed decision making.

The Science Panel on Interactive Communications and Health (Eng, 1999) concluded that few other health-related interventions have the potential of interactive health communications to simultaneously improve health outcomes, decrease health care costs and enhance consumer satisfaction. New information technologies, such as the Internet and World Wide Web, combine the attributes of both mass and interpersonal communication. Yet, they should not replace older but effective strategies including mass media, one-on-one counseling, and tailored print communication (Strecher, 1999). Existing and new technologies should be integrated based on scientific knowledge to provide a menu of choices. http://scipich.health.org/pubs/finalreport.htm

The increasing complexity of every element of cancer communications, from the understanding of cancer itself, to the rapid evolution of new media, to the recognition of the manifold needs of diverse audiences, demands a broad, bold interdisciplinary approach. Bringing people together from different disciplines can accelerate the speed with which discoveries are made, translated into researchable hypotheses and then turned into products that benefit people. A recent IOM report, *Bridging Disciplines in the Brain, Behavioral and Clinical Sciences,* stressed that "solutions to existing and future health problems will likely require drawing on a variety of disciplines and on approaches in which interdisciplinary efforts characterize not only the cutting edge of research, but also the utilization of knowledge" (IOM, 2000, p.2). The challenges of cancer communications will not be surmounted if disciplines work in isolation.

A significant increase in the size of the cancer communications enterprise is needed to develop the next generation of research and interventions. At the same time, the enterprise must be informed by a greater understanding of the mechanisms by which these communications work and a commitment to diffusion. The result should be both sound knowledge and practical strategies to enhance cancer communications and improve the control of cancer.

III. Purpose of RFA

The Centers of Excellence in Cancer Communications Research (CECCRs) are expected to conduct research that will lead to major scientific advances in knowledge about cancer communications and their translation into practice. Specifically, the goals are to:

- Increase the number of investigators from relevant disciplines who focus on the study of cancer communications as part of interdisciplinary teams.
- Increase the number of peer-reviewed publications in the area of communication processes.
- Generate basic research evidence to improve understanding of the processes underlying effective cancer communication.
- Produce evidence-based communication interventions that can be used to modify cancer risk behaviors and improve informed decision-making and quality of life.
- Support novel interdisciplinary research to inform medical and public health practitioners about how best to communicate to the public, patients, and cancer survivors.
- Increase the number of evidence-based interventions in under-studied areas, e.g., diagnosis, treatment, survivorship and end-of-life, and on understudied populations.
- Train interdisciplinary investigators capable of conducting cutting-edge communications research directly relevant to the context of cancer prevention, detection, treatment, control, or survivorship.

The focus can include, but is not limited to, cancer risk communication, evidence-based interventions to enhance cancer communication, communication methods for diverse and under-served populations, innovative communication strategies to increase informed decision making and participation in clinical trials, communication about genetic testing, survivorship and end of life issues, as well as communication interventions to improve cancer prevention and early detection behaviors. We also invite research to elucidate the psychological mechanisms underlying the cancer communication process, understand how people use cancer information, test innovative strategies to overcome the digital divide in access to cancer-related information, and develop and evaluate methods to enhance the dissemination of evidence-based cancer communication interventions. Researchers are encouraged to examine the ethical issues associated with cancer communications as well as the cost-effectiveness of evidence-based interventions. Messages and the way messages and information are developed, designed, displayed and communicated should be based on scientific evidence, and these areas represent avenues of potential inquiry. Centers can conduct basic, intervention and diffusion research in a variety of settings, including laboratory, clinical and

community settings. They do not have to cover all aspects of the cancer continuum; focus is expected. However, there should be a focus on translatability – from basic to intervention research to application and sometimes back again, depending on the problem.

Where possible, evidence-based research products should be put quickly into the public domain through Web-based access using open source tools. CECCRs investigators will be encouraged to share tools not only among themselves but also with the larger community. Software and other tools, such as common gateway interface (CGI) scripts and interactive data-gathering tools, should be thoroughly documented for purposes of replication and dissemination. Investigators must provide evidence that they have a mechanism in place by which to disseminate evidence-based products and interventions that emerge from this research. Unnecessary reliance on or production of proprietary technologies that inhibit dissemination and replication is discouraged.

Applicants are encouraged to collaborate with other organizations. These may include any of the following, but the Centers are not required to do so nor are they limited to them: NCI-designated Comprehensive Cancer Centers, Cancer Information Service, Special Populations Networks, and other NCI-funded research projects, such as the Cancer Family Registries, Cancer Genetics Networks, Transdisciplinary Tobacco Use Research Centers as well as the Centers for Disease Control and Prevention, the American Cancer Society and other voluntary health associations, the Robert Wood Johnson Foundation, National Science Foundation grantees, and industry. In addition, collaborations should be considered with universities, including Schools of Public Health, Historically Black Colleges and Universities, public health agencies, community technology centers and other organizations. The active participation of advocacy groups and appropriate community organizations is encouraged. Relevant collaborations with NIH intramural programs can be included as well.

IV. Research Questions

The level of specialization in different aspects of cancer communications research will vary from center to center, e.g., topics, points on the cancer continuum, populations, levels of analysis and types of research. However, the Centers should focus thematically on areas in which there are significant gaps in knowledge and critical needs--where focused, collective, interdisciplinary efforts could make a difference. It is expected that the CECCRs will catalyze problem solving and lead to more rapid advances in knowledge than would be possible by depending on individual investigators working in relative isolation. CECCRs should contribute to understanding what works and what does not work and why. In most cases, the studies will require a recognition of the cognitive, affective, and sociocultural influences on health behaviors. The sine qua non of the Centers consists of at least 3 research projects with an integrative theme, cores and plans for career development and use of developmental funds. Investigators are encouraged to include research projects that bridge basic and intervention research.

Potential Research Topics

Note that these are examples only and will not constitute evaluation criteria.

<u>Elucidate Basic Mechanisms in Cancer Communications</u>

- Answer questions about the mechanisms by which cancer messages exert their impact, including mediators of cancer risk communication.
- Clarify how people seek, process and use health information and develop a greater understanding of how cognitive and emotional factors affect processing (Croyle, Sun, and Hart, 1997; Park et al., 1999).

- Develop improved methods for visually communicating numerical and other complex information.

Explain the Communication Process

- Increase understanding of how people search for, use and respond to cancer information within the changing information environment and how this is affected by individual factors such as age, ethnicity, income, culture and personality.

Improve Decision Making

- Qualitative and quantitative research are needed to improve understanding of how patients process complex information about the benefits and risks of different medical options and make decisions in the face of considerable uncertainty (Croyle & Lerman, 1999).
- Examine the impact of interventions to improve cancer-related decision making and the impact of activated patients upon patient-physician communication and family communication.

Improve Risk Communication

- A number of important topics in risk communication research were identified as high priorities by experts who attended an NCI-sponsored meeting on cancer risk communication (December 1998). The papers from the meeting were published in a September, 1999 supplement to the ***Journal of the National Cancer Institute*** and include many potential topics.

Improve Communication for Diverse Audiences

- Promote knowledge about, access to and use of cancer information for low literacy and other diverse audiences as well as children and adolescents affected by cancer.

Design More Effective Interventions

- Conduct research that contributes to an effective menu of communication choices for different audiences, including traditional communication methods, such as mass media, one-on-one and small group education strategies, print and telephone communication strategies; proactive strategies, such as telephone counseling and tailored print communications; and interactive technologies, such as the Internet, kiosks and CD-ROMs. What is the optimal mix of communication strategies? How do presentation and format interact to affect message impact? How can interventions be combined to maximize their impact?
- Conduct research on the relative contribution to improved outcomes of varying amounts of message intensity, complexity, burden on receivers, and development costs. Evaluate stepped-care approaches to communications. Examine contributions to health outcomes, including health care costs, health care utilization, and quality-adjusted life years saved.
- Examine the impact of integrated communications systems that include multiple channels of communication, including interpersonal, intrapersonal, mass media and new media to give people the information they want, how they want it, when and where they want it.

Use of the New Media

Wired for Health (http://scipich.health.org/pubs/finalreport.htm) and the recent IOM report *Networking for Health* (http://www.nap.edu/catalog/9750.html) make a number of suggestions for research on the new media. Applicants interested in new media research are encouraged to consult these sources. Potential topics include:

- Examine potential use of the Internet and other media for informed decision making, health monitoring and feedback and improved communication between physicians and patients.

- Develop strategies to overcome the Digital Divide and involve diverse populations in use of cancer-related applications on the Internet and elsewhere.

Improve Interpersonal Communication

- Examine the role of interpersonal, including physician and/or nurse and patient communication and group communication in promoting information decision making, psychosocial adjustment, personal adaptation, and social support for individuals confronting cancer.

Understand and Improve Diffusion of Best Practices

- Research is needed to develop more effective communication-related diffusion strategies.
- Identify the fundamental mechanisms that enhance diffusion to populations in contrast to the basic mechanisms underlying individual change over time.

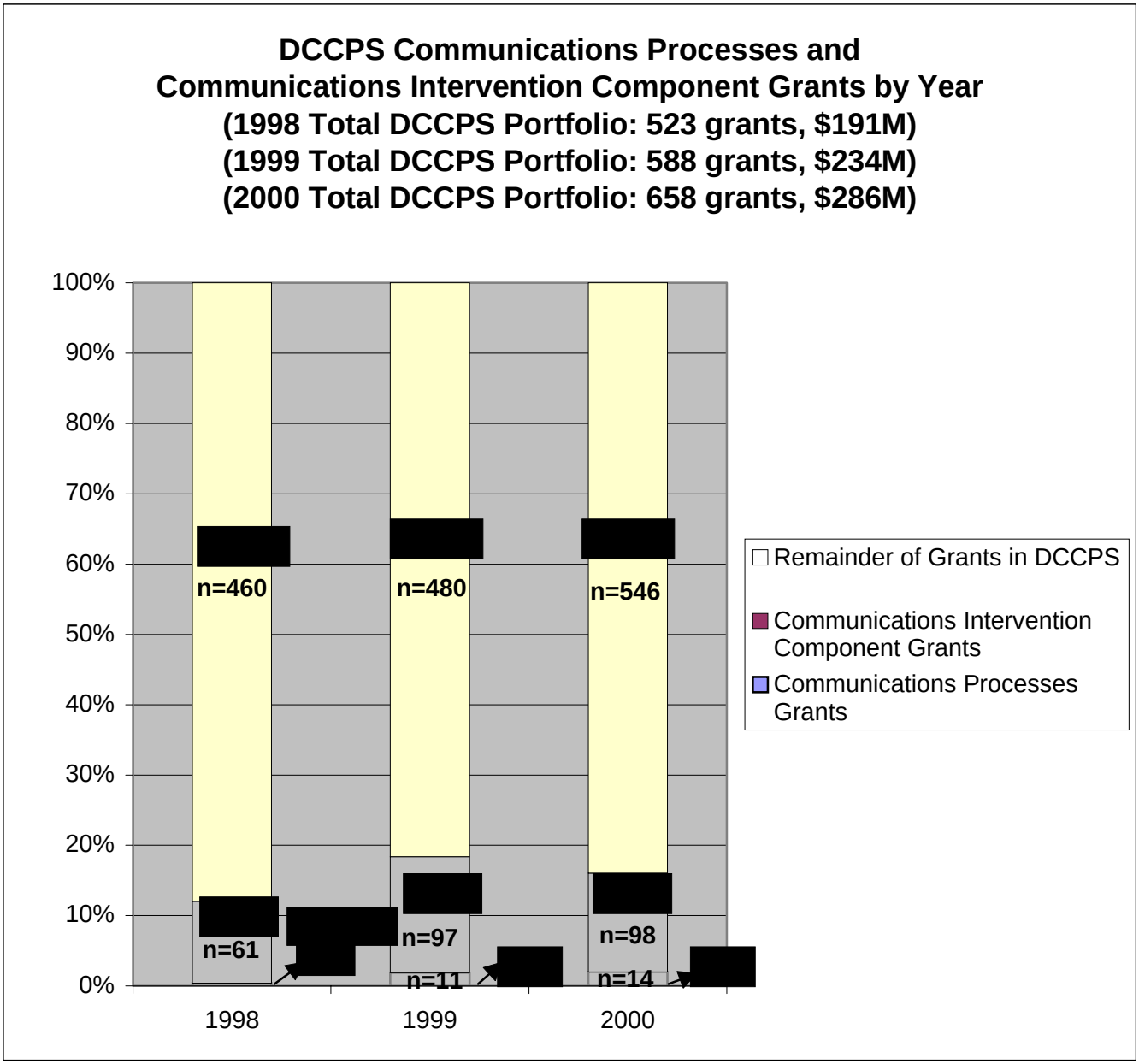
Restrictions on Applications

- The NCI now funds many studies that compare tailored print interventions to usual care interventions or "Kitchen Sink" interventions to usual care. However, when these studies have not been successful in achieving significant impact, it usually has not been possible to identify the reasons. Research funded under this initiative should not be limited to studies that focus only on outcomes. Rather, the studies should represent a major advance in terms of innovation, theory testing, intervention strategy and methodology. A major emphasis should be to understand what works, what does not work and why, in order to identify general principles and processes of communication.
- In addition, research exclusively focused on health professionals is not appropriate.
- Proposals that are exclusively focused on outreach or service delivery also are not acceptable.

V. Portfolio Analysis of Funded Cancer Communications Research

There has been a significant deficit in the scope of NCI extramurally funded research programs that focus on explicating the complex processes underlying cancer communications. Such research is desperately needed to inform communications practices throughout the cancer continuum. While there has been a pattern of growing interest in cancer communications-related research in extramural programs over the last several years, few funded studies have focused directly on examining the process of cancer communications and/or have manipulated critical elements of cancer communications in such a way that their effects can be assessed. This has led to duality in cancer communications-related research, with relatively few cancer communications-specific studies that directly examine the mechanisms underlying cancer communications processes, and relatively more general communications studies that use communication as interventions. Cancer communications research remains an unfulfilled area for extramural investigation.

The Figure below illustrates the number of DCCPS grants that focus on cancer communications processes and those that include one or more cancer communications intervention components and the proportion they represent of all DCCPS grants. The CECCR initiative is designed to facilitate comprehensive, programmatic, and interdisciplinary research to increase our understanding of cancer communication processes and ultimately, to increase the impact of communication strategies employed to reduce the national cancer burden.



VI. Justification for Use of RFA Mechanism

This RFA uses the National Institutes of Health (NIH) specialized center grant (P50) mechanism. In addition to support for interdisciplinary research projects, support also is provided for career development, developmental research projects, specialized resources and shared core facilities. PIs will be responsible for the planning, direction, and execution of the proposed CECCR program.

The NCI's P50 centers mechanism was chosen because of its stated objective of translating basic research findings to applied, innovative research with patients and populations, with the ultimate objective of reducing cancer risk, incidence and mortality, and improving quality of life. Centers include fully developed research projects, innovative pilot projects, a career development program, cores, and other resources dedicated to translational research objectives.

There is an urgent need for new investigators who have the quality and breadth of training necessary to conduct cutting-edge health communications research. Such training should expose young investigators to multiple levels of interdisciplinary health communications research and applications. Because health communications research scientists are widely dispersed by

geography and discipline, this type of training is difficult to obtain. By emphasizing meaningful integration and collaboration among scientists, the Centers will provide a challenging and unique venue for training the next generation of health communications researchers. Each CECCR will provide career development opportunities for new and established investigators. These scientists may wish to pursue active research careers in interdisciplinary cancer communications research, communicate with other CECCRs on a regular basis to share information, assess scientific progress in the field, identify new research opportunities, and promote inter-CECCR collaborations to promote discovery and to resolve areas of scientific controversy. In this way, this initiative addresses many of the training issues raised in the IOM's *Bridging Disciplines* report and the National Research Council's report on addressing the national changing needs for biomedical and behavioral scientists.

VII. Budget

This RFA is a one-time solicitation. NCI expects to make 4 to 5 awards, depending on the number of applications of high scientific merit and availability of funds. Applicants may request up to five years of support. The NCI anticipates setting aside up to $10 million for the initial year's funding.

The policy for centers grants establishes the following limits to the requested budgets: A new P50 application may request a maximum annual direct costs of $1.5 million and maximum annual total costs of $2.5 million. In complying with the direct costs cap of $1.5 million, the indirect costs related to subcontracts to other institutions or organizations will not apply toward the direct costs cap, but the total dollar request may not exceed $2.5 million. Future year increases are limited to three percent and may not exceed this cap. The total project period for an application submitted in response to this RFA may not exceed five years. The anticipated award date is March 2002.

VIII. Timeline

BSA Presentation: November 16-17, 2000
Release Date: February 1, 2000
Letter of Intent Receipt Date: March 15, 2001
Application Receipt Date: July 11, 2001
Review of Applications: September/October 2001
Fund Applications: March 2002 (Fiscal Year 2002)

IX. References

1. Abrams DB, Mills S, Bulger D. Challenges and future directions for tailored communication research. *Annals of Behavioral Medicine* 1999; 21(4):299-306.
2. Cancer Risk Communication: What we know and what we need to learn. *Journal of the National Cancer Institute Monographs* 1999; (25).
3. Croyle, RT, Lerman, C. Risk communication in genetic testing for cancer susceptibility. *Journal of the National Cancer Institute*, 1999; 25: 59-66.
4. Croyle, RT, Sun, Y, Hart, M. (1997). Processing risk factor information: Defensive biases in health-related judgments and memory. In K. Petrie & J. Weinman (Eds.), *Perceptions of Health and Illness: Current Research and Applications* (pp.267-290). London: Harwood Academic Publishers.
5. Cyber Dialogue. (October 27, 2000). Internet health seekers reach critical mass. *Cyber Dialogue Re:Sources*. http://www.cyberdialogue.com/resource/press/ releases/2000/05-23-cch-future.html.
6. DHHS. *Healthy People 2010* (Conference Edition, in Two Volumes). Washington, DC: January 2000.
7. Eng TR, Maxfield A, Patrick K, Deering MJ, Ratzan SC, Gustafson DH. Access to health information and support: A public highway or a private road? *JAMA* 1998; 280(15) 1371-5.
8. Eng TR, Gustafson DH, Henderson J, Jimison H, Patrick K. Introduction to evaluation of interactive health communication and applications. *American Journal of Preventive Medicine* 1999; 16(1) 10-15.
9. Entwistle VA, Sheldon TA, Sowden A, Watt IS. Evidence-informed patient choice: Practical issues of innovating patients in decisions about health care technologies. *International Journal of Technology Assessment in Health Care* 1998; 14(2) 212-225.
10. Fiore, MC, Bailey, WC, Cohen, SJ, et al. *Treating Tobacco Use and Dependence*. Clinical Practice Guideline. Rockville, MD: U.S. Department of Health and Human Services. Public Health. June 2000.
11. Harris Poll. (December 22, 1999). Online population growth surges to 56% of All Adults. *The Harris Poll*, #76.
12. Hornik, R. (1997). Public health education and communication as policy instruments for bringing about changes in behavior. In M.E. Goldberg, M. Fishman (ed); et al. *Social Marketing: Theoretical and practical perspectives. Advertising and consumer psychology*. (pp. 45-48). Mahwah, NJ, U.S.: Lawrence Erlbaum Associates, Inc., Publisher. xv, 457 pp.
13. Institute of Medicine and National Research Council Report: Ensuring Quality Cancer Care (1999). Washington, D.C: *National Academy Press*.
11. Institute of Medicine: Bridging Disciplines in the Brain, Behavioral, and Clinical Sciences (2000). Washington, D.C: *National Academy Press.*
12. Kreps GL, Bonaguro EW, Query JL Jr (1998). The history and development of the field of health communication. In L.D. Jackson and B.K. Duffy (eds.), *Health Communication Research*, (pp. 1-15). Westport, CT: Greenwood Press.
13. Lerman C, Hughes C, Croyle RT, Main D, Durham C, Snyder C, Bonney A, Lynch JF, Narod SA, Lynch HT. Prophylactic surgery decisions and surveillance practices one year following BRCA 1 / 2 testing. *Preventive Medicine* 2000; 31:75-80.
14. Miller TE, Reents S. The health care industry in transition: The online mandate to change. *Cyber Dialogue for Intel Corporation* 1998.
15. O'Connor AM, Fiset V, DeGrasse C, Graham ID, Evans W, Stacey D, et al. Decision-aids for patients considering options affecting cancer outcomes: evidence of efficacy and policy implications. *Monogr Natl Cancer Inst* 1999; 25:67–80.
16. Park, DC, Morrell, RW (ed); et al. *Processing of medical information in aging patients: Cognitive and human factors perspectives.* (pp. 199-219). Mahwah, NJ, USA: Lawrence

Erlbaum Associates, Inc.
17. Patrick K. Prevention, public health, and interactive health communication. *American Journal of Preventive Medicine* 1999;16(1) 46-47.
18. PC Data Online. (April 26,2000). Net Portrait & trade; Reveals demographics of home Internet users in U.S. *PC Data Online Reports*. http://wwwpcdataonline.com/press/pedo042600.asp.
19. Roter, DL, Hall, JA. (1992). *Doctors talking with patients/patients talking with doctors: Improving communication in medical visits*. Westport, CT, USA: Auburn House/Greenwood Publishing Group, Inc., xii, 203.
20. Skinner CS, Campbell MK, Rimer BK, Curry S, Prochaska JO. How effective is tailored print communication? *Annals of Behavioral Medicine* 1999; 21(4):290-298.
21. Strecher, VJ, Greenwood, T, Wang, C, Dumont, D. Interactive multimedia and risk communication. *Monogr Natl Cancer Inst* 1999; 25:134-139.
22. Thorne, SE. Communication in cancer care: What science can and cannot teach us. *Cancer Nursing* 1999; 22(5): 370-378.
23. Science Panel on Interactive Communication and Health. *Wired for health and well being: The emergence of interactive health communication*. Office of Disease Prevention and Health Promotion. U.S. Department of Health and Human Services, 1999. Washington, D.C.
24. Whaley, BB (ed) et al. *Explaining illness: Research, theory, and strategies*. LEA's Communication Series. (pp. 171-194). Mahwah, NJ, U.S.: Lawrence Erlbaum Associates, Inc.